

Missouri **ORGAN DONATION**

2008 ANNUAL REPORT



*Give thanks.
Give life.*

GOVERNOR'S ORGAN DONATION ADVISORY COMMITTEE



Letter from the CHAIR

CONSENT AND INTENT... MISSOURI'S TWO DONOR REGISTRIES

Dear fellow Missourians,

Everyone within the organ and tissue donation field is hailing the passage of the revised Uniform Anatomical Gift Act (UAGA). In general, the revisions address and clarify problematic wording in the 1968 UAGA. The 1968 UAGA clearly intended for individuals to be able to donate their organs by signing a donor card or the back of their drivers' licenses, but the language was not strong enough to be legally binding. Consent from a donor's next of kin was still necessary.

The revised UAGA of 2008 focuses on the right of a living person to direct his or her anatomical gifts after death. The main tool to implement this process will be a new, separate donor registry initiated by affirming one's choice at Missouri's Department of Revenue offices at the time of driver's license renewal or by direct sign up via the Internet. The new registry process is designed to be legally valid and can be used as the sole consent necessary to fulfill the deceased's wishes.

The new "consent" registry is in the process of being built. Meanwhile, the current "intent" registry will continue to be a viable resource to determine the intentions of a person to become a donor. As always, consent from the next of kin is needed when a person dies and his or her name appears on the "intent" donor registry. Names from the "intent" registry will never be automatically transferred to the "consent" registry. The "intent" registry will no longer accept new additions, but it will continue to be a resource.

Thus, Missouri will soon have two donor registries for many years to come, much like other states that have passed similar revised UAGA legislation. Hospital personnel dealing with organ and tissue donation may start to hear of potential donors being on the "consent" registry or the "intent" registry (or both). It's a subtle, but important difference, designed to make a difference in granting the wish of the donor and providing much-needed organs and tissues to those waiting for a transplant.

Your support and encouragement are deeply appreciated.

With greatest respect,

Ron Walkenbach, PhD
Chair, Missouri Governor's Organ Donation Advisory Committee



New for 2009

In the spring of 2008, the Missouri Legislature passed key changes to the state's organ and tissue donor registry. The Governor signed those changes into law, effective August 28, 2008. Now, it's a first-person consent registry that makes a donor's decision final unless revoked in a manner provided by law. Family consent is no longer required. Those enrolled before August 28, 2008, are asked to enroll again to obtain the first-person consent status by going online at www.missouriorgandonor.com or by saying yes when obtaining or renewing a permit or driver/nondriver license.

A complete list of the statutes pertaining to organ donation can be found online at:
www.dhss.mo.gov/organdonor/LawsRegs.html

DHSS Vision

Healthy Missourians for life.

DHSS Mission

To be the leader in promoting, protecting and partnering for health.

Organ Donor Program Mission

Inform Missourians about the importance of and need for organ and tissue donation, maintain a central registry, and reduce the gap between the need and availability for organs and tissues.

The Missouri Organ Donor Registry is Voluntary and Confidential

You do not have to belong to the registry to be a donor. Talk with your family and express your choice to be a donor. Joining the registry will put your decision in writing. To join the registry, visit www.missouriorgandonor.com.



Letter from the D#SS DIRECTOR

Dear fellow Missourians,

On behalf of the Missouri Department of Health and Senior Services, I am pleased to receive and extend to you the 2008 Annual Report of the Governor's Organ Donation Advisory Committee. The report highlights the generosity of Missourians and the overwhelming need for organ and tissue donors. You will find heart-warming stories of mothers who never gave up hope for their babies waiting for a transplant; people who reached out to virtual strangers to give the gift of life; and volunteers, many of whom have benefitted themselves from a transplant, and who spread the word about the importance of organ donation. I'm especially pleased to report one of my own co-workers recently received a new kidney, thanks to the generous act of a donor... someone just like you. All these stories show just how important organ and tissue donation can be and how the simple act of becoming a donor can change and save the lives of up to eight people.

The Department of Health and Senior Services continues to be an active participant on the Missouri Donor Designation Collaborative Team, better known as Team Missouri. Since the collaborative began in October 2006, organ donor registry enrollment has increased from 2.1 million to 2.4 million registrants. The Department of Health and Senior Services, on behalf of Team Missouri, the committee, and other partners that comprise the Donate Life Missouri Consortium, secured a grant to redesign the current registry with plans for completion in 2009. The grant will fund such changes as allowing registrants to better define personal donor designations, establishing a personal login and password to modify personal donor designations at any time, and creating a system to notify family and friends of the decision to donate.

I'd like to take this opportunity to thank Committee Chair Dr. Ron Walkenbach, who continues to be a strong advocate for organ and tissue donation and serves to help meet the needs of his fellow Missourians. Through his leadership and guidance and actions of the committee, the lives of Missourians will continue to be enhanced. I'd also like to welcome Tammy McLane of Mid-America Transplant Services as the newest member of the Governor's Organ Donation Committee. All of the committee's efforts in promoting the gift of life are humbling.

Thanks to all of the partners in the Donate Life Missouri Consortium for continued support of the Missouri Organ Donor Program.

Sincerely,

Jane Drummond
Director, Department of Health and Senior Services

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Organ Donation Advisory Committee **SUMMARY**

CHARGE

- Develop organ donor awareness programs to educate the public about the importance of organ donation.
- Recommend priorities in the expenditures from the Organ Donor Fund.
- Submit a report of activities and recommendations to the Governor, General Assembly and director of the Department of Health and Senior Services.

COMMITMENT

- Support the Department of Health and Senior Services in maintaining an effective and efficient donor registry.
- Encourage partnership and collaborate in efforts to provide educational activities at the local and regional levels.
- Review and recommend to the department actions needed to increase donor awareness while maximizing the Organ Donor Fund's limited resources.
- Encourage fund donations to support educational efforts and registry maintenance and enhancements.

MEMBERSHIP

The Governor's Organ Donation Advisory Committee is a ten-member committee comprised of: four organ procurement agency representatives; four organ recipients, families of organ recipients, organ donors or families of organ donors; one health care representative (hospital); and one Department of Health and Senior Services representative. Each member serves a five-year term. The Governor appointed Tammy McLane during fiscal year 08. Additional committee information can be found at www.dhss.mo.gov/organdonor/Board.html.

Procurement Agency Representatives

Jan Finn, *Midwest Transplant Network*

Tammy McLane, *Mid-America Transplant Services*

Ronald Walkenbach, PhD, *chair, Heartland Lions Eye Bank and cornea recipient*

Vacancy

Hospital Representative

Michael Perry, MD, *kidney recipient*

Donor or Recipient Family Representatives

Lisa Atkins, *living organ donor*

Lisa Britt, DVM, *heart recipient*

Lori Hodges, *donor family*

Peter Nicastro, *double lung and kidney recipient*

Department Committee Liaison

Virginia Beatty, *Organ Donor Program*

Committee Member Appointed and Confirmed in 2008



Tammy McLane

Tammy McLane: Ms. McLane respectfully accepted Missouri Secretary of State Robin Carnahan's appointment of membership to the Governor's Organ Donation Advisory Committee and was confirmed during the 94th General Assembly on February 6, 2008.

For the past 10 years, McLane has committed herself to saving lives through excellence in organ and tissue donation by working in community education and as Director of Corporate Communications at Mid-America Transplant Services (MTS), a not-for-profit organ procurement organization in St. Louis.

McLane earned a Bachelor of Science in speech communications, with an emphasis in public relations, and minored in journalism at Southern Illinois University at Carbondale. She is currently working on her master's degree in communications management from Webster University.

"I am honored to serve my commission and fulfill my duties as a member of this dedicated team, which helps close the gap between the need and availability for organs and tissues in Missouri."

Volunteering creates a national character in which the community and the nation take on a spirit of compassion, comradeship and confidence.

-Brian O'Connell

Volunteers, Cindy Gibson, Ila Watts, Judy Smith, and Bob and Pattie Spencer, are highlighted on pages 4 and 5.

New kidney opens new chapter in my life

by Tyronne Allen

It's the difference between life and death. That is how I describe my health after receiving a donor kidney. My name is Tyronne Allen. I am the Librarian at the Missouri State Supreme Court Library, and I'm very happy someone decided to give me the chance to see that difference. My life before receiving my donor kidney was a life battling diabetes for 35 years that took a toll on my kidneys. When my kidneys failed, I began dialysis treatments.

I am like many other African-Americans, who, along with Asian-Pacific Islanders and Hispanics, suffer disproportionately from end-stage renal disease compared to Caucasians. In fact, while minorities make up only about 20 percent of the U.S. population, they comprise more than half of the people on the national organ transplant waiting list. The chances of an organ transplant being successful are greatly improved if organs are matched between people of the same race or ethnic background, making it important for more minorities to sign up to be organ donors.

When you start receiving treatments at the dialysis clinic, they ask if you would like to sign up to receive a donor kidney. I took that advice, conferred with a transplant center and immediately went on the waiting list. Like every organ donor recipient, I had to have just the right match. I had several people offer me kidneys — my wife, family members and even deacons at my church. But none of those people was quite the right match. It's a common problem for those waiting on the organ donation list: plenty of offers but few matches. So as I waited the three years it took to find the right match, I continued dialysis.

Don't get me wrong. Dialysis is a wonderful tool that helped keep me alive. But it is exhausting. I went to the dialysis center for four-hour sessions, three times a week. These treatments were in addition to the busy schedule I kept at the office. There were many days when I wouldn't finish with dialysis until nearly 8 p.m., leaving me just enough time to go home, rest a little from the tiring dialysis process, eat supper and get ready to face another busy day, another day of waiting and hoping for a donor kidney.

"It was on Easter Sunday when I received my new kidney. That's a special blessing."

I would get a call at two in the morning when it was icy outside telling me that there was a possible match. I have to admit, it was a scary process. Finally, after three years, I got the final call. It was on Easter Sunday when I received my new kidney. That's a special blessing, and I think God was really good to me for that.

It's been five years since I received my new lease on life, and I feel great! I no longer have to take dialysis treatments, I can travel, but most importantly, I feel so much healthier! I remember the nurse saying to me, "I don't want to see you back here, Tyronne, because the reason most people come back to the hospital is they don't take their medicine." I've never forgotten that. I remain faithful and take my anti-rejection medications that I need to help my body accept my new kidney.

My hope now is that more people will sign up for the organ and tissue donor registry, including African-Americans, Asian-Pacific Islanders and Hispanics, so others might get their own new lease on life. More donors give the doctors the largest possible pool from which to choose. I know there are not enough donors out there, and I hope a lot of people will donate their kidneys, because it really changes the quality of life for the recipient.

When you die, you can't use it anyway. It would be nice to give to someone who needs help. If I could be on the organ donation list, I would. A donor gave me a wonderful gift — my new life. I hope that people will consider giving as a gift, and know that their families will be blessed as well. Please feel free to share my story with others. A recording of my story is available at www.dhss.mo.gov/organdonor/publications.



Tyronne Allen, donor kidney recipient

My Living Donor Story

by Tina Rickard



Rosemary (left) and Tina (right)

My donor story began in December of 2004. I'm an administrative assistant in the Woodhaven Human Resource Office and handle the employee benefits program for Woodhaven. Rosemary, another employee at Woodhaven, came into my office to ask questions regarding her health insurance coverage because she had polycystic kidney disease and had reached the point of needing dialysis or a transplant in the near future. I immediately asked what I needed to do to be tested as a donor for her. At first Rosemary was hesitant and in shock that I had offered. I learned her brother had the disease, her mother had passed away from it, and her father didn't meet the age requirement to be a donor. She was not expecting someone to offer. We talked about the process on several different occasions, and, after much convincing, Rosemary passed my name on to her transplant team.

On December 16, 2004, I met with the transplant team to go over the process of being tested. The testing process took approximately one month. I scheduled an appointment to meet with the transplant team to discuss what was involved with the testing, and appointments were scheduled at that time to do blood work and a urinalysis test. The first round of testing was completed, and then they scheduled an EKG. The testing process was extremely simple, and after approximately one month of testing, I received "the call." It was January of 2005, and I was sitting in my office at Woodhaven when I learned that I was a match. I immediately called my husband and mother to let them know the good news!

At that point there was a lot of discussion with my husband, children and mother about what the living donation process would entail, such as when the surgery would take place, how long I would be in the hospital, how long I would be off from work, etc. I had the full support of my family and friends, although they worried about how difficult it would be on me. My own belief from day one, when I learned Rosemary needed a kidney, was that God gave me

two good kidneys — you can live a perfectly normal life with one — so I must be meant to share one.

I believe many people would consider being a living organ donor if they better understood the process and misconceptions were eliminated. I must have been told 50 times by friends and family during the six months of preparation that the surgery would be so much harder on me, the donor. This is so untrue. I checked into the hospital the morning of June 14, 2005, for my surgery, and after two (2) days in the hospital, I was on my way home. I spent two weeks recovering with my friends and family waiting on me hand and foot. The third week I found I was more independent but still moving a little slower than normal. By the end of that third week I was playing third base in my favorite sport, softball!

Rosemary's hospital recovery took approximately one week before she was able to go home. She was surrounded by her friends and family who took care of her during her recovery. She was away from work for approximately 12 weeks and is doing absolutely

"Many people would consider being a living organ donor if they better understood the process and misconceptions were eliminated."

wonderfully. While we were recuperating in the hospital, the doctors told us that her kidney began working before they even stitched her up. She has had tremendous success with the transplant.

I am blessed to say that I'm still working with Rosemary, and I receive thanks from her every time I see her. Rosemary says I was a blessing to her. Actually, I feel I received the blessing because giving a gift of life, in any form, is a blessing that no one can describe. I will continue to advocate for the living organ donor program by telling my story. I was asked by the transplant team if I would be available to talk to potential donors if they had questions, and I said absolutely yes. I have spoken with one potential donor and would be happy to do that on a regular basis.

Rosemary and I would love to share our story on a national level through newsletters, talk shows, etc. We have both sent e-mails to talk show hosts and have shared our story with a lot of people we come in contact with daily. I have become a member of the Missouri Organ Donor Registry and have encouraged all of my family members and friends to do the same.

If you or someone you know is considering this generous gift and would like to visit with someone who has gone through it, I would love to talk to you. You can e-mail me at tinarickard@myparklane.com.

Volunteers are ESSENTIAL

The Department of Health and Senior Services works with several organizations that help promote Missouri's registry and educate individuals about organ and tissue donation including, but not limited to: the Midwest Transplant Network (MTN); Mid-America Transplant Services (MTS); Heartland Lions Eye Banks (HLEB); the Gift of Life Foundation (GOL); Missouri Kidney Program (MKP); and Second Wind of St. Louis. Within each of these organizations, there are many, many volunteers who passionately spread the word and dispel myths about organ and tissue donation. They also inform and encourage registry enrollment. Here are their stories:

A Mother's Hope and Love



*Cindy Gibson, volunteer,
and her son Xavier*

My son Xavier was born with a severe congenital heart defect called hypoplastic left heart syndrome. He had three open heart surgeries by the time he was 13 months old. Xavier went into heart failure shortly after the last surgery. The doctors told us they didn't feel he would survive another surgery on his heart, and that his only chance for survival was to receive a heart transplant.

It was hard sitting at home waiting for a heart to become available. We realized

that meant another child had to die and it was hard to think about.

We realized how lucky we were that Xavier did receive a heart, even though he later passed away. We will be forever grateful to his donor and their family; if not for their decision, Xavier would not have had a second chance at life.

Our family knew that we needed to do something to help increase awareness of the importance of being an organ and tissue donor. I, along with members of my family, signed up to volunteer for the Midwest Transplant Network, and I volunteer as much as I can. We also have our own nonprofit organization called Xavier's Heart to Heart. We have participated in 18 events: health fairs, fall festivals, benefits and speaking engagements.

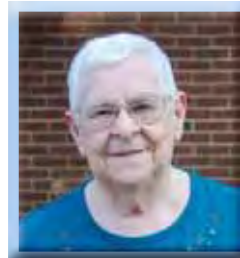
Volunteering for the Midwest Transplant Network is something that I find very rewarding. I have witnessed the amazing result of transplants. While it did not turn out the way we would have liked, I know transplants save many peoples' lives. I am hoping by helping

to raise awareness of eye, organ, and tissue donation, that those waiting for a second chance at life will receive it, just as Xavier did.

Cindy Gibson, volunteer, Midwest Transplant Network

Gift of Sight Helps Artist Reclaim Independence

Ila has always relied on her keen sense of sight to capture the details in her artwork. As a photographer and needlecraft hobbyist, vision is her most precious tool.



*Ila Watts, cornea
recipient and volunteer*

However, as Fuchs' corneal dystrophy took its toll, Ila's vision became so blurred that she could no longer pass the test to renew her driver's license.

In 2007, Ila underwent two transplant surgeries, in March and in June, to restore her vision. Both of the transplants were successful, and today Ila has been able to pick up many of her favorite hobbies again. She has also been able to live a much more independent lifestyle since her surgeries.

Ila has gone through training with the Midwest Transplant Network and the Heartland Lions Eye Banks to become a Sight Ambassador volunteer. As part of her volunteer work with the Heartland Lions Eye Banks, Ila's photography will be featured on our holiday card this year. The images captured by her camera truly express her joy of renewed vision.

Annie Kuhl, Missouri Lions Eye Research Foundation

Optimism in the Face of Adversity



*Judy Smith, volunteer
and heart recipient*

Adversity is no stranger to Judy Smith from Kansas City. She had a full plate with three teen-age children and as co-owner of an automotive repair business with her husband. Unfortunately, her father-in-law had a stroke, compelling him to live with the family, and Judy added caregiver to her list of responsibilities. Her caregiving role expanded after her father-in-law passed away, when her husband also had a stroke requiring home care. Forced to close their business, a very weary Judy paid a visit to her cardiologist and heard, "You cannot go home because you need a heart transplant. Is there someone who can pick up your car?" That was in 2003.

In contrast to her story, hopeful, optimistic and spiritual are the words that come to mind when you meet Judy for the first time. She has worked very hard since her transplant to keep her family together and just started a new job. In November 2008 she completed the training course to become a Life Mentor for Gift of Life in Kansas City. These special mentors provide encouragement and support to new transplant candidates, their families and caregivers. Mentoring begins at the time of evaluation and continues through the mentee's first year post-transplant. If anyone can make a difference and provide encouragement, it is Judy Smith.

Learn more about Judy and the Life Mentors program at www.giftdonor.org.

Keith Anderson, Gift of Life-Kansas City

Volunteers are Essential continued on Page 5



Bob and Pattie Spencer in front of the 2008 Donate Life float in the Rose Parade. A portrait of their daughter, Dana, was a florograph on the float.

Touching So Many Lives

"Parents will always remember their children. But their greatest fear is that others will forget them." This sentiment, expressed by a donor mom, still resonates strongly with Bob Spencer. It is one of the reasons he and his wife, Pattie, participate in donor family events. It helps them to see others remember and honor their daughter, Dana, whose life was cut short in an auto accident.

Dana Spencer was an energetic, bubbly, outgoing young woman. Bob and Pattie learned about new people moving to their neighborhood through Dana. She was the one who would initially introduce herself and welcome newcomers. Then she would say to her mom and dad, "Guess who moved into so-and-so's house?"

"She was always the kid on the corner waving hi to everyone," describes Pattie. She started babysitting before she was 12 years old. All of the kids loved her and asked their parents to get her to come back because they had the most fun with her. Before Dana died, she worked in a kiosk at West County Shopping Center. She knew everyone so well at the mall that after she passed, they had a blood drive in her honor. Even at work, she touched so many lives.

It has been 11 years since Dana passed away, but her spirit and memory continue to live on in so many different ways – not only through the recipients of her organs and tissues, but also through the many stories that those who love her continue to share.

Bob and Pattie take every opportunity they can to share their story, whether at national events or local venues such as hospital and community presentations. From lending a helping hand in the office, to answering phones on a phone bank, to serving on committees to represent the donor family perspective, the Spencers are always willing to help. They have been active volunteers with Mid-America Transplant Services for many years. Becoming involved helps them to honor their daughter and keep her memory alive.

A Chance Encounter

Ninette Querimit, MTS Corporate Communications Specialist

by Bob Spencer

The media followed Justin Hughes' (the young man who received Dana's heart) story, so Pattie and I knew what he and his family looked like. It is strange how fate works. One day, about two months after the transplant, I was trudging down Broadway on my way to work. I had been told that Justin's mom, Vanessa, worked at Boatmen's Bank, but I never expected what was about to happen.

On the same sidewalk, coming toward me was a tall, African-American woman. I'd never seen her in person, but I knew her instantly. It was Vanessa Hughes.

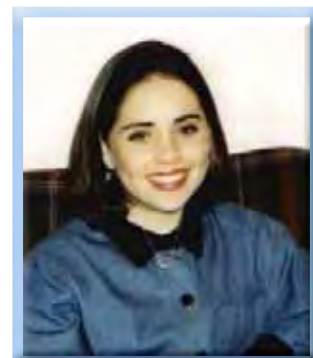
Should I say hello? Could I say hello? "Mrs. Hughes?" was all I could get out. She looked at me funny, but replied, "Yes..." "I'm Dana Spencer's father."

It seemed to take her a second for the name to register. Then, a flood of emotions ran across her face. Mine too, I imagine.

I can't remember exactly what happened next, but I know she hugged me, I hugged her, and we stood there crying on each other's shoulders right there on Broadway and Washington at eight o'clock in the morning.

In the subsequent years, we have been blessed to be able to get to know the Hughes family. Pattie and I have watched Justin grow and flourish. We were saddened to see the family move to Philadelphia, and then happy when they moved back.

We still miss our Dana so much; she was such a joy. But it helps to know she lives on. She lives, not only in Justin Hughes, but also in his brother Larry, and in their mother Vanessa, too. But, in addition, she lives in other recipients, not only those who got one of her organs, but in any recipient. She lives on in the hands of the surgeons who perform those miracles. She lives in the hearts of people who just signed their donor cards, in the caseworkers at Mid-America Transplant Services who go out and ask families to make a very tough decision. Dana's memory lives on every Thursday morning when volunteers are stuffing envelopes. And she is smiling that smile...that wonderful, beautiful smile.



Dana Spencer

Editor's note: In 2006, Justin Hughes passed away. His mother, Vanessa, says they still feel blessed to have had the extra time that Dana's precious gift of life gave them.

Educational INITIATIVES

ORGAN DONOR AWARENESS EFFORTS

The Missouri Department of Health and Senior Services (DHSS) promoted organ and tissue donation throughout the fiscal year. The Governor's Organ Donation Advisory Committee approved a number of new initiatives. In addition, the Midwest Transplant Network, Mid-America Transplant Services, and Heartland Lions Eye Banks conducted educational efforts. Visit their Web sites for more details about past and upcoming events.

- ⊗ Program staff worked closely with the Governor's office to promote organ and tissue donation. Sample scripts were drafted for the Governor, who recorded and distributed a public service announcement (PSA). The PSA can be heard at www.dhss.mo.gov/OrganDonor/Publications.html.
- ⊗ The state's organ procurement organizations, the Midwest Transplant Network and Mid-America Transplant Services, sponsored a Capitol Days on April 9, 2008. The Governor issued a proclamation highlighting the importance of organ donation and issued a news release informing Missourians how they could sign up on Missouri's registry. Many volunteers, donor families, and recipients gathered at the state's capitol to meet with their legislators to discuss the importance of organ and tissue donation and the revision of the Uniform Anatomical Gift Act, as well as to provide educational booths for capitol visitors, legislative staff, and legislators.
- ⊗ DHSS worked with the Governor on the Give 5 – Saves Lives challenge. The Governor sent a challenge via e-mail on April 16, 2008, to all state employees asking them to learn about organ and tissue donation and to make a decision. The challenge also asked those who decided to be donors to record that decision on the registry and to notify their families of the decision. The e-mail included information about one of Missouri's employees, Ms. Rhonda Kremer, who was on the wait list for a kidney. Her story is available at www.dhss.mo.gov/OrganDonor/Publications.html (Ms. Kremer received a new kidney in October 2008). The Governor stated, "Giving of one's self to save the life of another person is the greatest gift a person can offer. Being an organ, tissue, or blood donor truly is a generous and selfless act. I am among the 2.36 million Missourians who have already said yes to organ and tissue donation by signing up for the Missouri Organ Donor Registry. If you're already on the registry, I extend to you my gratitude. If you're not, please consider signing up." He further stated, "If you choose to be an organ and tissue donor, take an additional five-minute break one day this week, log onto the web from your workstation, and sign up for the registry. As a state employee, you have a positive impact on the lives of others every single day. Becoming a member of the organ donor registry is just one more opportunity to make a difference." A follow-up news release was issued on April 24, 2008, "Missourians Respond Big to the Governor's Request to Donate Life." The release highlighted an all-time high one-week registry enrollment of 1,433 individuals and again encouraged individuals to sign up and stated where they could obtain more information.
- ⊗ DHSS "on-hold" messaging for the spring and summer months of 2008 included scripts for organ and tissue donation. In addition, a "What's New" information line was included on the DHSS home page for the month of April.
- ⊗ The program purchased "Donate Life Month" posters and distributed them throughout DHSS buildings, to local driver license contract offices, to Department of Revenue field coordinators, to the Red Cross, and to Show Me Healthy Women providers. Some of the Show Me Healthy Women providers also distributed brochures containing more information about organ and tissue donation.
- ⊗ DHSS placed a half-page ad in the April issue of *Rural Missouri*. The ad provided readers the web address to register their decision about organ and tissue donation. *Rural Missouri* has a monthly readership of one million. The same ad was used as an electronic payroll stuffer for all state of Missouri employees.
- ⊗ DHSS collaborated with the Midwest Transplant Network to provide an informational booth at the Hickman Health Fair on April 11, 2008, at Hickman High School in Columbia, Missouri. Allan Bell, a donor family member and Columbia police officer, joined in the effort. Brochures about organ and tissue donation were given to interested high school students. Staff in attendance helped answer students' questions.
- ⊗ The April issue of *Missouri Life* included a one-page story in the "Show-Me Health, Missouri Topics and Concerns" section. Writer Stefanie Kronk told the story of donor Sydney Pikey and her family, titled "The Gift of Life, Organ Donation Turns Tragedy into Triumph." The magazine has a reach of 600,000 readers, 540,000 of them Missourians.
- ⊗ DHSS issued a news release in April 2008 for National Donate Life Month and featured Ms. Beulah Langford's decision to donate her grandson's organs. The decision not only helped six people, it inspired her to spend hundreds of hours encouraging others to become organ and tissue donors. The release generated four radio interviews, and several other stations broadcast stories about donation. The Midwest Transplant Network, Mid-America Transplant Services, and Heartland Lions Eye Banks were all instrumental in this process and assisted by sending out additional news releases and being available for interviews at local radio stations.
- ⊗ The Red Cross worked with DHSS to distribute registry brochures throughout the state fiscal year at local blood drives across the state. In addition, the Red Cross included information in its electronic newsletter, displayed posters, and placed a registry link on its web site. DHSS posted links to the Red Cross site and provided materials for the agency.

Educational Initiatives continued on Page 7

Waiting for Hope



We've all had to spend time waiting. Waiting for the bus. Waiting for dinner. Waiting with great anticipation for a special holiday to arrive. But the longest wait would have to be the one upon which your life depends. Rhonda Kremer is going through that kind of wait.

"I've been on the organ donation wait list since August 2007, hoping for a new kidney," says Kremer, a fiscal administrative manager in the Office of Financial and Budget Services for the Missouri Department of Health and Senior Services.

"It started one day with a nose bleed at work that I just could not get to stop. I went to my doctor, and after several tests, the diagnosis was that my kidneys were not functioning right."

Kremer has focal segmental glomerulosclerosis, a disease that scars the kidneys' filters, keeping the vital organs from doing their job of cleaning the body of waste materials. Right now, she undergoes dialysis treatments, but doctors tell her those treatments only do about 13-17 percent of what a normally functioning kidney does. In addition, the process is lengthy and requires her to spend 3 ½ hours each time she

goes to dialysis... three times a week. Kremer has also had to restrict what she eats to what is called a renal diet: reduced phosphorous, potassium, salt and even liquid intake.

Kremer's family members eagerly stepped up to be donors, but unfortunately, either they didn't match or their own health issues kept them from donating a kidney.

Kremer's not alone in her wait. While millions in Missouri have signed up on the Organ Donor Registry, there are still more than 1,600 Missourians who wait for a life-saving organ donor transplant. Most hope for a new kidney. Since Kremer's waiting for a "cadaver donor," doctors can't really tell how long it might be until she gets a new kidney.

Despite the obstacles, Kremer remains optimistic. She knows that if enough people sign up, an eventual match will be found.

"I'd just like to make an appeal to everyone to take a few minutes and sign up on Missouri's Organ Donor Registry," says Kremer. "You can make a difference."

UPDATE!!!

In October 2008, Rhonda had to wait no longer as a donor kidney was found for her. As of press time, she is recovering.

Educational INITIATIVES *continued*

- ⊙ DHSS asked the University of Missouri to add a short article about organ and tissue donation and the registry to its weekly electronic newsletter. The newsletter is sent to all University of Missouri employees. Special thanks go to Dr. Lisa Britt, Ms. Lori Kramer Clark, Ms. Christina Vollrath, and Ms. Jo Leisman for their assistance and sponsorship in assuring the article was published.
- ⊙ The Midwest Transplant Network sponsored an extensive Donor Sabbath Campaign in November 2007. The organization mailed postcards to all churches in its service area (two-thirds of the state of Missouri), providing information about National Donor Sabbath and how to get additional information. Churches that responded to the postcard received materials and technical support to promote organ and tissue donation among their congregations and to educate about how to sign up in the donor registry. While National Donor Sabbath is typically held two weekends before Thanksgiving, many churches in Missouri hosted events at various times throughout the year.
- ⊙ DHSS sponsored a Capitol Days in February 2008. The Organ Donor Program hosted an educational booth. In addition, a laptop computer was available for online registrations.
- ⊙ "The Oprah Winfrey Show" had a special edition on organ and tissue donation in January 2008. DHSS recorded an increase of 2,300 hits to its organ donor web page over the same month the previous year. In addition, a total of 367 online enrollments were received the day of the talk show and two days following the show.
- ⊙ Talk show host Montel Williams dedicated a portion of his February 20, 2008, show to organ and tissue donation. A donor mother and recipient appeared and met for the first time to discuss their experience and gratitude. Twenty-three online registrations were received in the days following the show.
- ⊙ The Midwest Transplant Network participated in the Health Disparity Results meeting in Kansas City, Missouri, organized by the DHSS's Office of Women's Health. Isaac Ruffin provided information about minorities and organ and tissue donation, and transplantation. He stressed the importance of minorities making a decision, discussing it with their families, and recording their decision in the registry.

The Missouri Organ Donor Registry is *Voluntary* and *Confidential*

For more information, please call 888-497-4564 or visit us online at www.dhss.mo.gov/organdonor.

To register your donor decision, visit www.missouriorgandonor.com

Financial SUMMARY

STATEMENT OF ACTIVITIES

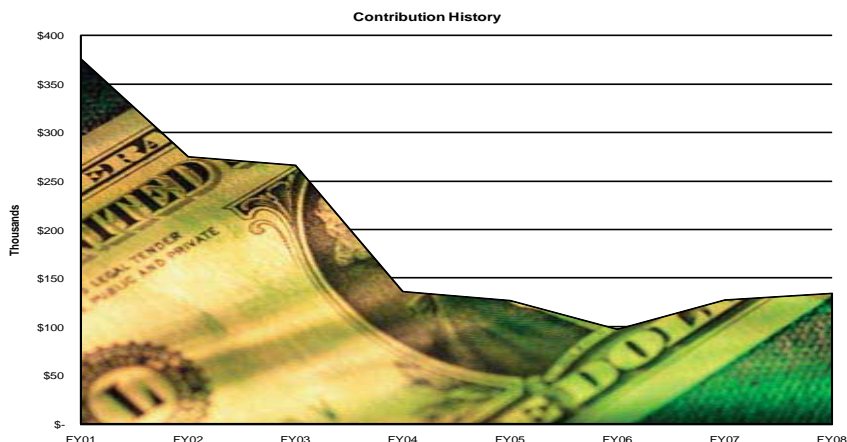
Fiscal Year (FY) Ended June 30, 2008, and 2007

	FY08	FY07
Fund Revenues		
Contributions/Interest		
Department of Revenue contributions	131,933	124,896
Direct contributions	2,469	2,725
State Employee Charitable Campaign.....	311	0
Investment interest	47	322
Total revenue.....	\$134,760	\$127,943
Fund Expenses		
Registry		
Participation	3,862	218
Operations	28,567	740
GODAC Meeting.....	93	151
Adjustment — Prior information technology balance.....	-19,630	0
Educational initiatives/annual report.....	4,994	4,567
Evaluation/focus groups	0	0
Personnel services/leave pay.....	52,459	56,205
Staff benefits (fringe benefits).....	23,016	25,716
Administrative overhead		
Indirect costs.....	17,585	20,423
Network allocation	3,304	3,596
Program supplies and expenses	425	651
Total expenses	\$114,675	\$112,267
Beginning Fund Balance	496,624	445,665
Change in Net Assets		
Income	134,760	127,943
Network Adjustment.....	45	0
Indirect Adjustment	-8,526	35,283
Expenditures	(114,675)	(112,267)
Ending Fund Balance.....	\$508,499	\$496,624

The Organ Donor Program is exclusively supported by voluntary contributions, with the majority of contributions being made at driver's license and motor vehicle offices. After six years of declining revenue, the fund saw a slight increase for FY07 and FY08. FY08 contributions totaled \$134,760, an approximate 5.3 percent increase over FY07 revenues of \$127,943.

Expenditures increased for FY08 due to minor adjustments in salary and other related costs. The department will continue to monitor expenditures in order to secure a healthy fund balance to maintain registry operations for years to come.

The statement of activities presented here is the responsibility of the Department of Health and Senior Services. These financial statements reflect fund activity during Missouri's state fiscal year. Questions should be directed to Office of Finance and Budget Services, Department of Health and Senior Services, P.O. Box 570, Jefferson City, MO 65102-0570.



Donation and Transplantation in MISSOURI

The United Network for Organ Sharing (UNOS) is a non-profit, scientific and educational organization* that administers the nation's only Organ Procurement and Transplantation Network (OPTN). The OPTN collects and manages data about every transplant event occurring in the United States, facilitates the organ matching and placement process, and brings together medical professionals, transplant recipients and donor families to develop organ transplantation policy. UNOS' mission is to advance organ availability and transplantation by uniting and supporting our communities for the benefit of patients through education, technology and policy development.

* UNOS is qualified as a charitable organization under section 501 (c)(3) of the IRC

MISSOURI DATA – DONORS AND WAITING LISTS

Based on OPTN Data as of September 26, 2008*

NUMBER OF REGISTRANTS EVER WAITING

with Missouri as home state.....**2,213**

CANDIDATE Age at Listing

for the Period of July 1, 2007 – June 30, 2008

<1	20
1-5	27
6-10	13
11-17	48
18-34	339
35-49	652
50-64	902
65+	212

NUMBER OF DECEASED DONORS RECOVERED

with Missouri as home state (7/01/95 - 6/30/08).....**1,024**

DONOR Age at Listing

for the Period of July 1, 2007 – June 30, 2008

<1	3
1-5	8
6-10	4
11-17	18
18-34	59
35-49	57
50-64	47
65+	25

* Data is subject to change due to future data submission or correction. UNOS Data Request 091508-3. This work was supported in part by Health Resources and Services Administration contract 234-2005-370011C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

MISSOURI DONORS FLUCTUATE

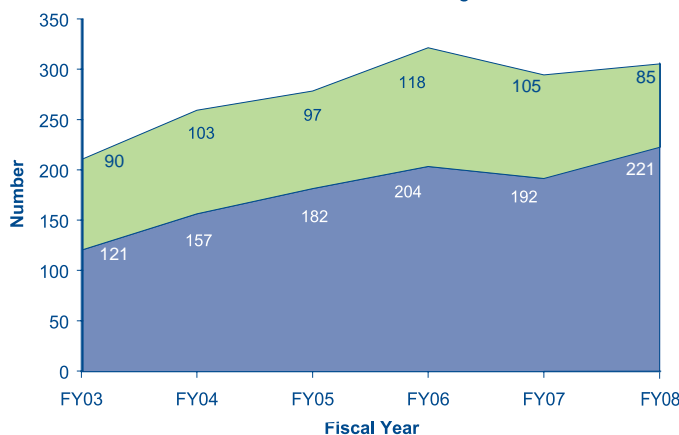
The number of Missouri residents and their families saying yes to donation is increasing slightly, while the numbers of actual donors fluctuate. The general health of the donor and the circumstances surrounding death influence the number of lives impacted by organ and tissue donation. The chart below illustrates a slight increase during FY08 in the number of donors recovered, and the overall trend is positive. UNOS reports that 1,282 individuals were registered and waiting for a transplant on June 30, 2008. (UNOS data dated September 7, 2007.)

One organ donor can save the lives of up to eight organ recipients and as many as 50 people can benefit from tissue gifts. Lifesaving gifts through organ donation include the kidneys, liver, lungs, heart, pancreas and small intestine. Tissue transplants include heart valves, blood vessels, skin, bones, connective tissues and the corneas of the eyes. Even people with chronic health conditions, such as diabetes, high blood pressure and hepatitis, can provide lifesaving gifts through organ and tissue transplantation.

The graph below reflects the number of Missouri residents who donated organs (living and upon death) and the number of transplants performed where the recipient state of residency was Missouri. The bar graph clearly illustrates the need for organs continues to increase at a faster rate than donation. The figures in the chart are based on a state fiscal year (July – June).

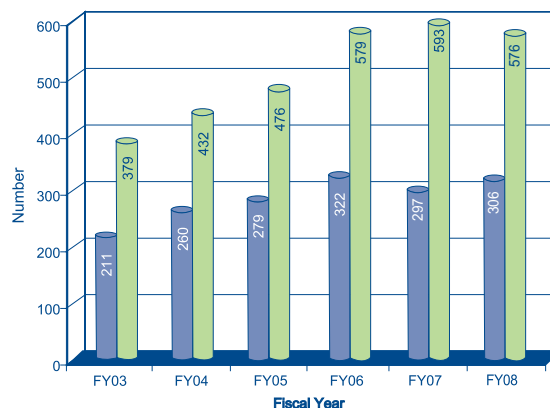
Missouri Donors by Fiscal Year (FY)

■ Deceased Donors ■ Living Donors



Number of Donors Compared to Number of Transplants Performed

■ Missouri Donors ■ Transplants Performed Where Residency was Missouri



* Data is subject to change due to future data submission or correction. UNOS Request 091508-4. This work was supported in part by Health Resources and Services Administration contract 234-2005-370011C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

Registry **ENROLLMENT**

ENROLLMENT CONTINUES TO GROW

The Missouri Organ Donor Registry participation data is analyzed by program staff and partners and is used as a tool to evaluate education and awareness activities. Staff and partners also target future education activities based on registry data. As educational efforts and awareness among Missouri residents increase, program staff expects to see an increase in percentages and total number of enrollments. Fiscal year (FY) 08 recorded 2.41 million Missourians, of all ages, in the confidential registry of potential donors. In addition to registering at any Department of Revenue license office in the state, online enrollment is available and a quick and easy alternative. To register online, visit the secure site www.missouriorgandonor.com. A third option is direct enrollment, in which an individual prints the enrollment form, completes it, and then submits it to the Department of Health and Senior Services. Individuals who register using the online service and direct enrollment methods receive a confirmation letter within 30 days. During FY08, the department recorded the following enrollment activity:

Online Enrollment.....	3,777
Direct Enrollment.....	5,084
Department of Revenue.....	441,970

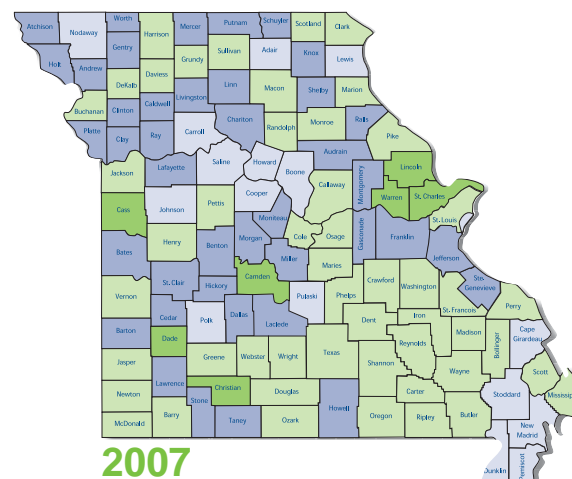
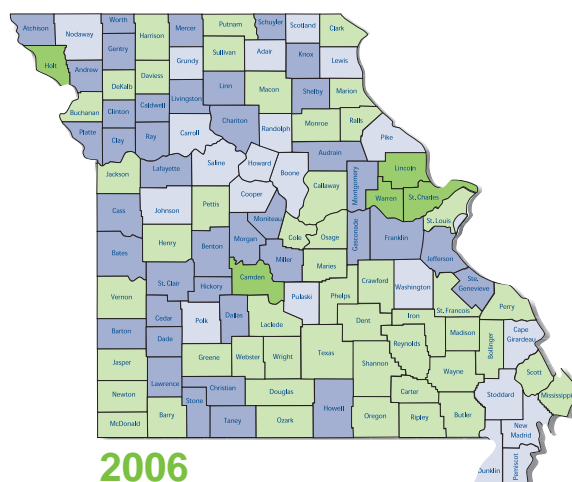
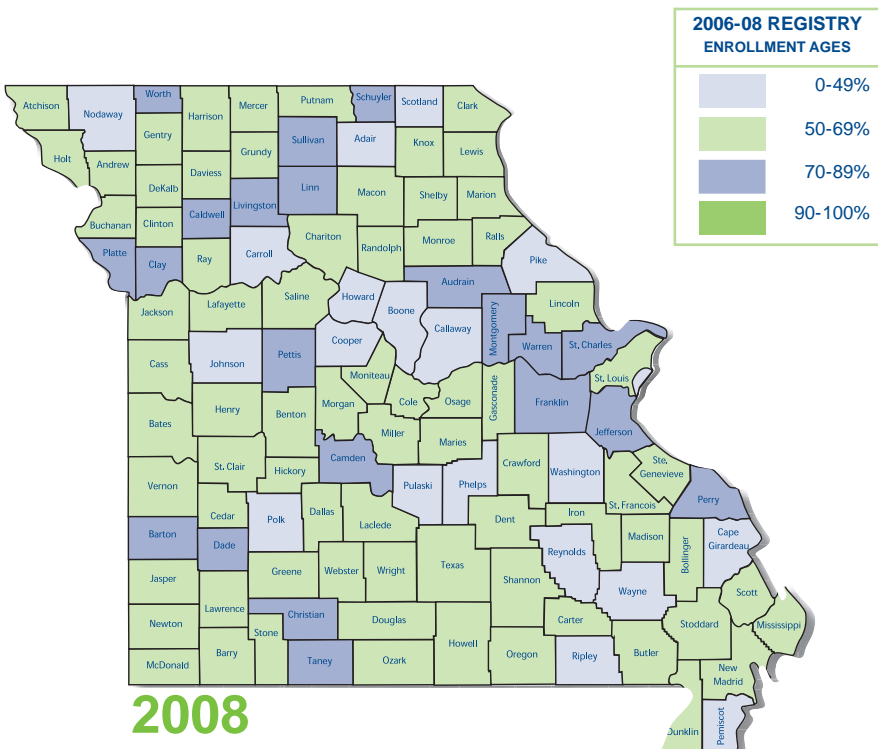
Missouri has recorded its highest level of registry participation to date. The maps below illustrate the comparison of registry enrollment data between fiscal years. Using 2000 Census and registry data, the FY06 map illustrates that 94 counties have 50-100 percent of the 18- to 24-year-old age group enrolled in the registry. Of these counties, five are at a 90-100 percent enrollment rate. Using the same parameters, the FY07 map highlights that 96 counties have 50-100 percent of the 18- to 24-year-old age group enrolled in the registry, and of these counties, seven are at a 90-100 percent enrollment rate. The FY08 map reflects 95 counties have 50-100 percent of the 18- to 24-year-old age group enrolled in the registry.

The age range of 18 to 64 is used as a primary indicator of registry demographics, since the majority of adults in this category are licensed drivers and are given the opportunity to participate in the registry when obtaining a license or identification card. Using the 2000 Census data for Missouri, an average of 58 percent of Missouri residents 18 to 64 years of age were enrolled statewide for FY08.

A complete list of registered adults 18 to 64, enrolled by contract fee offices, is available on Page 11.

Registry Enrollment

18- TO 24-YEAR-OLD AGE



To learn more about the registry, please call 888-497-4564 or visit the program Web site at www.dhss.mo.gov/organdonor.

Registry PARTICIPATION



ORGAN DONOR REGISTRY ENROLLMENT BY CONTRACT FEE OFFICE*

July 1, 2007 — June 30, 2008

ADAIR Kirksville25%	DENT Salem26%	LIVINGSTON Chillicothe34%	SCHUYLER Lancaster34%
ANDREW Savannah34%	DOUGLAS Ava23%	MACON Macon9%	SCOTLAND Memphis23%
ATCHISON Rock Port34%	DUNKLIN Kennett23% Malden16%	MADISON Fredericktown27%	SCOTT Chaffee31% Sikeston28%
AUDRAIN Mexico34% Vandalia36%	FRANKLIN Pacific40% St. Clair21% Sullivan23% Union37% Washington40%	MARIES Vienna25%	SHANNON Eminence20%
BARRY Cassville26% Monett31%	GASCONADE Hermann34% Owensville16%	MARION Hannibal35% Palmyra30%	SHELBY Shelbina25%
BARTON Lamar37%	GENTRY Stanberry33%	MCDONALD Pineville18%	ST CHARLES Harvester11% O'Fallon24% St. Charles27% Wentzville45%
BATES Butler36%	GREENE Glenstone41% Republic40% South Fremont41% Springfield30%	MERCER Princeton37%	ST CLAIR Osceola27%
BENTON Warsaw36%	GRUNDY Trenton30%	MILLER Eldon36%	ST FRANCOIS Bonne Terre20% Farmington29%
BOLLINGER Marble Hill28%	HARRISON Bethany26%	MISSISSIPPI Charleston28%	ST LOUIS AAA St. Louis30% Afton13% Bridgeton27% Chesterfield40% Clayton44% Creve Coeur41% Deer Creek21% Des Peres51% Ferguson22% Florissant12% North County5% Oakville40% Olivette30% Overland25% South County43% West County42%
BOONE Columbia42%	HENRY Clinton32%	MONITEAU California38%	ST LOUIS CITY Northside6% South Kingshighway24% St. Louis City Hall24%
BUCHANAN St. Joseph30%	HICKORY Hermitage36%	MONROE Monroe City36% Paris4%	STE GENEVIEVE Ste. Genevieve37%
BUTLER Poplar Bluff20%	HOLT Mound City36%	MONTGOMERY Montgomery City33%	STODDARD Dexter23%
CALDWELL Kingston37%	HOWARD Fayette38%	MORGAN Versailles27%	STONE Crane28% Lakeview/Branson West26%
CALLAWAY Fulton37%	HOWELL Mountain View29% West Plains31% Willow Springs32%	NEW MADRID New Madrid26%	SULLIVAN Milan24%
CAMDEN Camdenton40%	IRON Ironton25% Viburnum27%	NEWTON Neosho30%	TANEY Branson33% Forsyth32%
CAPE GIRARDEAU Cape Girardeau22% Jackson13%	JACKSON Blue Springs31% Grandview33% Independence14% Kansas City23% Lee's Summit47% Raytown30% Sugar Creek31%	NODAWAY Maryville38%	TEXAS Cabool22% Houston22% Licking32%
CARROLL Carrollton9%	JASPER Carthage37% Joplin38% Sarcoixie32%	OREGON Alton13% Thayer25%	VERNON Nevada33%
CARTER Van Buren29%	JEFFERSON Arnold35% De Soto27% High Ridge34% Imperial40% Twin City19%	OSAGE Linn34%	WARREN Warrenton26%
CASS Belton34% Harrisonville20%	JOHNSON Warrensburg36%	OZARK Gainesville34%	WASHINGTON Potosi16%
CEDAR Stockton33%	KNOX Edina29%	PEMISCOT Caruthersville18%	WAYNE Greenville20%
CHARITON Keytesville35%	LACLEDE Lebanon25%	PERRY Perryville33%	WEBSTER Marshfield43%
CHRISTIAN Nixa36% Ozark36%	LAFAYETTE Lexington30%	PETTIS Sedalia33%	WORTH Grant City33%
CLARK Kahoka35%	LAWRENCE Aurora31% Mount Vernon38%	PIKE Bowling Green26% Louisiana9%	WRIGHT Hartville30% Mountain Grove25%
CLAY Excelsior Springs33% Gladstone40% Liberty49% North Kansas City25%	LEWIS Monticello41%	PLATTE Parkville40% Platte City46%	
CLINTON Cameron40% Plattsburg39%	LINCOLN Elsberry29% Troy37%	PLATTE Parkville40% Platte City46%	
COLE Jefferson City38% Jefferson City Mail In32% Jefferson City Mini Branch36%	LINN Brookfield29%	POLK Bolivar30%	
COOPER Boonville37%		PULASKI Waynesville21%	
CRAWFORD Cuba26% Steelville22%		PUTNAM Unionville21%	
DADE Greenfield72%		RALLS New London25%	
DALLAS Buffalo24%		RANDOLPH Moberly30%	
DAVIESS Gallatin23%		RAY Richmond27%	
DEKALB Maysville31%		REYNOLDS Ellington License Office19%	
		RIPLEY Doniphan7%	
		SALINE Marshall35%	

* Registry participation is based on percent of total transactions responding "yes" to being placed on the registry.

If the fee agent changed during FY08, the percent may be skewed.

This publication was made possible by Missourians who provide voluntary contributions to Missouri's Organ Donor Fund and is available online at www.dhss.mo.gov/organdonor/Publications.html.



Alternate forms of this publication for persons with disabilities may be obtained by contacting the Missouri Department of Health and Senior Services at 888-497-4564. Hearing and speech impaired citizens telephone 800-735-2966. VOICE 800-735-2466.

AN EQUAL OPPORTUNITY/AFFIRMATIVE ACTION EMPLOYER
Services provided on a nondiscriminatory basis.



ORGAN DONOR PROGRAM

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573-522-2847 or toll-free 888-497-4564

www.dhss.mo.gov/organdonor
www.missouriorgandonor.com